

# ALS<sup>®</sup>

## ASSOCIATION

# Wisconsin Chapter

**ANNUAL REPORT**  
**YEAR ENDING JANUARY 31, 2021**

The ALS Association Wisconsin Chapter  
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## **A MESSAGE FROM THE CHAPTER PRESIDENT**

Dear Chapter Members and Friends:

This annual report covers the fiscal year February 1, 2020, to January 31, 2021, and developments since the end of the fiscal year.

The Chapter is Wisconsin's only organization dedicated to providing care, services, support, and advocacy to over 500 people living with ALS and their families in the State of Wisconsin. In January 2021, I was honored to be elected as President of the Chapter, led by individuals dedicated to this cause, including our volunteer Board of Directors, volunteer Leadership Team and incredibly hardworking staff.

My thanks to everyone involved in supporting the Chapter during these unprecedented times, and especially our staff. Every member of our staff, from usually part-time employees to those who regularly work nights and weekends, has stepped up in this time of crisis. It is through their generosity and dedication that we have been able to continue providing excellent services to individuals in Wisconsin living with ALS and their families, to provide public awareness and advocacy, and to fund cutting-edge ALS research.

As Care Services Director, Angie Pereira, RN, BSN, was very effective with the transition to virtual programs during the height of the pandemic. She was tasked with overseeing the staff and collaborating with ALS clinics, providers and community resources on a remote basis, and the continuation of care has been nothing but stellar. The Chapter is indeed fortunate for Angie's leadership as she administers existing Care Services programs and creates new ways to serve our constituents. In addition to Angie, the team members who performed extraordinary work last year, and continue to do so, are Care Services Coordinators Robin Stanczyk, RN, and Mary DeFrain-Jones, CSW, located in the Greater Milwaukee area, Diane Fergot, CSW, who was previously located in the Lakeshore/Fox Valley area and recently moved to Eau Claire, and Kristy Sharp, who is located in the Madison area. Janet Gauger, Program Support Assistant, and David Ferrie, Equipment Loan Coordinator also served vital roles on the Care Services team. We are pleased to announce that Kathleen Huevler, former Finance Manager for the Chapter, has recently joined the Care Services team as Program Coordinator, to replace Janet Gauger who has retired. Many thanks to Janet for her years of service. Another recent addition, Alyson Johnson, comes to us with a breadth of experience and contacts as Care Services Coordinator for Northeast Wisconsin.

The Chapter's Care Services Coordinators work directly with people living with ALS and their families, providing virtual, phone and in-person consultations to deliver information, support, and resources. Programs throughout the state include monthly Support Groups in Milwaukee, Oshkosh, Manitowoc/Two Rivers, Green Bay, Wisconsin Rapids, La Crosse, and Madison. These were converted to virtual groups with the addition of a state-wide support group that enabled many people living with ALS to attend, when they otherwise could not attend in person due to their physical and geographical limitations. Thanks to volunteer facilitators Meg Posorske in Wisconsin Rapids and Roxanne Fox and Carolyn Herman in La Crosse for their leadership, and to the families who banded together to form these groups. Caregiver support groups, offered in the Milwaukee and Fox Valley areas, were also converted to statewide virtual groups in May 2020. As noted, all support groups converted to Zoom meetings in March 2020. While we have resumed some in-

person meeting, we have continued to offer virtual options. We are mindful that scaling back our in-person meetings is likely, due to the ever-changing situation with the pandemic.

The Chapter's Augmentative Communication Program has grown exponentially due to the increase in need to communicate effectively and remotely. Likewise, we have experienced growth in our Equipment Loan Program due to the increase in need of durable medical equipment to improve safety and quality of life. My thanks to David Ferrie, our Equipment Program Coordinator, who, despite the pandemic, continued to fill the equipment needs of people living with ALS in Wisconsin from sites in Milwaukee, Appleton, and Eau Claire. The Brian Trinastic Memorial Grant Program also continued to provide grants to individuals living with ALS for transportation, home modifications, communication devices and other needed equipment. Since its inception in 2009, hundreds of grants have been awarded to people living with ALS in Wisconsin.

Fundraising during a pandemic, especially when the market was on a roller coaster and people's employment was uncertain, is a challenging task. Fortunately for the Chapter, our fundraising and development team met the challenge head on, reinventing existing fundraisers like the Walks (more on that below), creating new online fundraisers, and dedicating substantial effort to grant writing. Thank you to the Chapter's Executive Director Melanie Roach-Bekos and Development Manager Susie Reed for their stellar efforts. Susie and Cheryl Brooks, our Outreach Community Coordinator, took the lead, and very successfully increased the Chapter's grant writing efforts, especially in Northeast Wisconsin. Taylor Skorik kept the Chapter in the forefront of social media including the Chapter's website, [www.als.org/wisconsin](http://www.als.org/wisconsin), Facebook, and Instagram. The Fundraising and Development Team also created billboard campaigns and participated in television and radio interviews. We are happy to announce some more recent additions to our development team: Maggie Shelledy McAsey, Development Manager, Erin Maddox, Media & Marketing Coordinator, and Annie Maloney, Development Coordinator. We are grateful for the experience and expertise they bring to our Chapter.

Like many non-profits, the Chapter saw the cancellation of Chapter and family/community events due to the COVID-19 pandemic. After initially moving the *Evening of Hope*, our gala dedicated to funding research, from March 13, 2020, to July 31, 2020, we ultimately decided to cancel the event as it simply was not safe to host an event attended by nearly 700 people, including many people at high risk. Despite the cancellation, many generous supporters told us to keep their payment for *Evening of Hope* attendance as a donation or to roll it over to 2021. We are most grateful for their generosity.

The Chapter's signature events, the Walks to Defeat ALS, were very different in 2020. Instead of a gathering of thousands of people in different locations across the state, smaller groups of families and friends participated in MINI-WALKS – spreading awareness, raising money in their neighborhoods, and dressing as “ALS Super Heroes”. Due to the state of the pandemic, this format will continue in 2021 with a “Walk Your Way” theme.

I also wish to thank the Chapter's Leadership Team, a group of professionals dedicated to supporting the Chapter's work, who have provided substantial financial support through both in-kind contribution of services and facilitating the creation of partnerships with Wisconsin's business community. Thanks also to the ALS Ambassadors, a group of people primarily in their 20s and early 30s who have expressed an interest in supporting the cause. Group members are asked to attend at least two events, invite their friends to join them, and to spread the word about

the Chapter's work and services by word of mouth and social media. We had to put these events on hold in 2020 and hope to revitalize this team in 2022.

Special thanks to Board Members Carl Bahneman and Meg Posorske, for serving on the national level in the last fiscal year. Carl served on the Board of Representatives and Meg became a member of the Strategic Planning Committee. Additional thanks to Executive Director Melanie Roach-Bekos for serving at the national level on The ALS Association's Research Committee.

Kathleen Huevler, the Chapter's Finance Manger during the last fiscal year, has recently transitioned to the Care Services team. While outsourcing some of the accounting and reporting tasks, we are pleased to announce the recent addition of Katie Flach, our Accounting Administrator. We are appreciative of the perspective and experience that Katie has brought to our team.

The Chapter Board of Directors, staff members and volunteers are dedicated and committed to the Chapter's mission. I thank all of them, and the Chapter's supporters, for their efforts.

Sincerely,

*Mary*

Mary Brennan-Druml  
President, Board of Directors

## **PROGRAMS AND SERVICES**

The ALS Association Wisconsin Chapter is very pleased to provide a variety of services to people living with ALS and their families and caregivers across the state. During 2020, we quickly adapted our programs to virtual options to continue to provide greatly needed services. Those programs include:

### ***Care Services Staff***

The Chapter's Care Services Staff provides services to people living with ALS, their families, and their caregivers, helping them learn about the disease, locate resources in the community and cope with the changes occurring in their lives. During the year ending January 31, 2021, the Chapter served nearly 600 Wisconsin residents living with ALS who were registered with the Chapter. Care Services programs and services listed below are available to assist individuals and families to meet the daily challenges of ALS.

### ***ALS Support Groups***

The Chapter reaches out to people living with ALS, their families, and their caregivers through support groups in Milwaukee, Oshkosh, Manitowoc/Two Rivers, Wisconsin Rapids, La Crosse, Green Bay and Madison. Support group meetings are upbeat gatherings that focus on coping with ALS and its challenges in the best way possible. We modified our groups in 2020 to virtual, Zoom options, while continuing with our standard format. Speakers discuss topics such as nutrition, insurance, communication devices, legal and financial issues, and breathing and swallowing problems with coping strategies. The meetings provide a supportive environment where tears, smiles and laughter are all part of the sharing experience.

Separate caregiver groups have met in Milwaukee, Appleton and Green Bay and we modified to include the entire state through a virtual option during 2020. The caregiver group is an informal gathering for individuals in a caregiving role, providing an opportunity to learn from, share with, and give and receive support from others who understand. In addition, caregivers in Milwaukee whose loved ones have passed away have formed a Next Chapter group. This group meets socially, participates in Chapter events and spends time together as they focus on the next chapter of their life without their loved one.

In 2020, we held nearly 75 virtual support groups which served 850 people with ALS, their families, friends, and caregivers.

### ***Wisconsin ALS Certified Treatment Centers of Excellence***

The ALS Clinic at Froedtert Hospital/Medical College of Wisconsin and The Clement J. Zablocki Milwaukee VA Medical Center ALS Clinic are recognized as Certified Treatment Centers of Excellence by The ALS Association. Thank you to Dr. Paul Barkhaus, Dr. Dominic Fee, Dr. David Shirilla, Angela Pereira, Mary Defrain-Jones and Robin Stanczyk for their dedication and service at the clinics.

The two Certified Treatment Centers of Excellence provide neurological diagnostics and imaging, as well as access to the services of a team of highly trained health care professionals specializing in ALS. Under the medical direction of Dr. Paul Barkhaus, Dr. Dominic Fee, and Dr. David Shirilla, the Clinic team consists of a Nurse Coordinator, Social Worker, Dietitian, Speech/Swallow Therapist/Augmentative Communication Specialist, Physical Therapist, Occupational Therapist, Respiratory Therapist, Chaplain, Child Life Specialist, Research Coordinator, Pharmacist and Wisconsin Chapter Care Services Representative.

Clinic visits were primarily virtual throughout 2020. We currently serve approximately 30 patients at the Froedtert ALS Clinic and 10-15 patients at the VA Clinic on a monthly basis.

In recent years, the Chapter provided expanded services at University Hospital & Clinics MDA ALS Clinic in Madison. Under the direction of Dr. Stephanie Gardon, the clinic is seeking to become a Recognized Treatment Center by The ALS Association, offering a high-quality approach to multidisciplinary care. The Chapter provides a member of the Care Services staff at each clinic to meet with patients and families to offer support and resources. Approximately 20 patients are seen at the clinic on a monthly basis.

The Chapter also supports a developing ALS Multidisciplinary clinic in the Neurosciences Center at Gundersen Health System in La Crosse, by providing a member of the Care Services staff at each clinic. This clinic is under the medical direction of Dr. Michael Leone and meets one to two times per month. Approximately 25 patients are currently being seen through this clinic.

### ***Equipment Loan Program***

The Chapter has an inventory of gently used durable medical equipment and assistive devices for loan at three sites in Wisconsin, thanks to the generous support and partnership with NuMotion, a statewide medical equipment company. The inventory includes wheelchairs, scooters, canes, walkers, grab bars, toilet seat risers, special utensils and other supplies and devices. The Equipment Loan Program has locations in the Milwaukee area, Appleton, and Eau Claire. During the year ending January 31, 2021, nearly 500 pieces of equipment were on loan to people living with ALS throughout Wisconsin. The Equipment Loan Program is one of the most highly utilized programs offered by the Chapter and was used extensively in 2020 to keep people safe and secure while sheltered at home.

### ***Augmentative Communication Program***

The Chapter maintains an inventory of gently used augmentative communication devices for loan for individuals with no or limited insurance coverage to obtain such devices if available. Devices range from low- to high-tech devices, based on individual need. The Chapter networks with and can provide resources for speech therapists, who are able to assess specific needs with respect to communication and communication aids. During the year ending January 31, 2021, nearly 150 pieces of equipment were on loan to people living with ALS in Wisconsin. Because virtual options were a necessity in 2020, this program became critical to give people the ability to keep in communication with their medical providers and loved ones.

### ***Brian Trinastic Grant Program***

The Chapter is pleased to provide transportation and flex grants through the Brian Trinastic Memorial Grant Program. These grants provide some financial relief from costs associated with ALS for individuals living in Wisconsin who are registered Chapter members. Two different reimbursement-type grants are offered under this program to help offset some of the high costs associated with an ALS diagnosis. Transportation grants help with the costs of travel and lodging associated with medical visits and Chapter events. Flex grants provide reimbursement for some out-of-pocket costs for medical equipment, home modifications, communication devices, ramps, and other needs. For the year ending January 31, 2021, 66 people living with ALS received grants totaling nearly \$45,000.

### ***Symposium and Youth Day***

The Chapter's ALS Care and Research Symposium has traditionally been held on an annual basis in the Milwaukee area. In 2020, the 16<sup>th</sup> Annual ALS Care and Research Symposium and Youth Day was delivered by an interactive website and hosted over 400 visitors from across the globe. Presenters included Dr. Richard Bedlack, Professor of Neurology at Duke University and Director of the Duke ALS Clinic; Dr. Paul Barkhaus and Dr. Dominic Fee, Neurologists, Froedtert/Medical College of Wisconsin; Dr. Andreea Anton, Pulmonologist, VA Medical Center; Melinda Kavanaugh, PhD, LCSW, with the Helen Bader School of Social Work at the University of Wisconsin-Milwaukee. Stories were shared by three of our chapter constituents living with ALS, presenting their special journey, including obstacles they have encountered and insights they have gained along the way.

Valuable information and resources were shared on the website, with the goal of providing education, guidance, services and support to ALS patients, their families, and their caregivers. We promoted public awareness and support to the ALS Association Certified Centers and affiliated ALS Multidisciplinary Clinics throughout Wisconsin.

A section on the website was dedicated to a special ALS Youth Program for children and teens ages 8-18 curated by Melinda Kavanaugh PhD, MSW, LCSW Associate Professor, Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee.

The website also featured local and national companies whose mission is to provide care, services, equipment and supplies to our ALS community.

Please continue to visit the site at [alsawicares.org](http://alsawicares.org).

**The ALS Association, Inc., Wisconsin Chapter**  
**Statements of Activities**

<i>Year Ended January 31, 2021</i>	Without Donor Restrictions	<u>With Donor Restrictions</u>		Total
		Program Services	Research	
<b>Support and revenue:</b>				
Special events - Net	\$ 394,314	\$ -	\$ 117,368	\$ 511,682
Advocacy/education and awareness	175,403	9,497	-	184,900
Contributions and other revenues	218,172	389,274	166,403	773,849
Grant revenue - Paycheck Protection Program	142,900	-	-	142,900
Net assets released from restrictions	684,234	(400,463)	(283,771)	-
<b>Total support and revenue</b>	<b>1,615,023</b>	<b>(1,692)</b>	<b>-</b>	<b>1,613,331</b>
<b>Expenses:</b>				
Program services:				
Patient and community services	746,571	-	-	746,571
Advocacy/education and awareness	331,501	-	-	331,501
Research	249,836	-	-	249,836
Management and general	131,470	-	-	131,470
Fundraising	99,860	-	-	99,860
<b>Total expenses</b>	<b>1,559,238</b>	<b>-</b>	<b>-</b>	<b>1,559,238</b>
Changes in net assets	55,785	(1,692)	-	54,093
Net assets at beginning of year	935,632	88,561	-	1,024,193
<b>Net assets at end of year</b>	<b>\$ 991,417</b>	<b>\$ 86,869</b>	<b>\$ -</b>	<b>\$1,078,286</b>

## The ALS Association, Inc., Wisconsin Chapter

### Statements of Functional Expenses\*

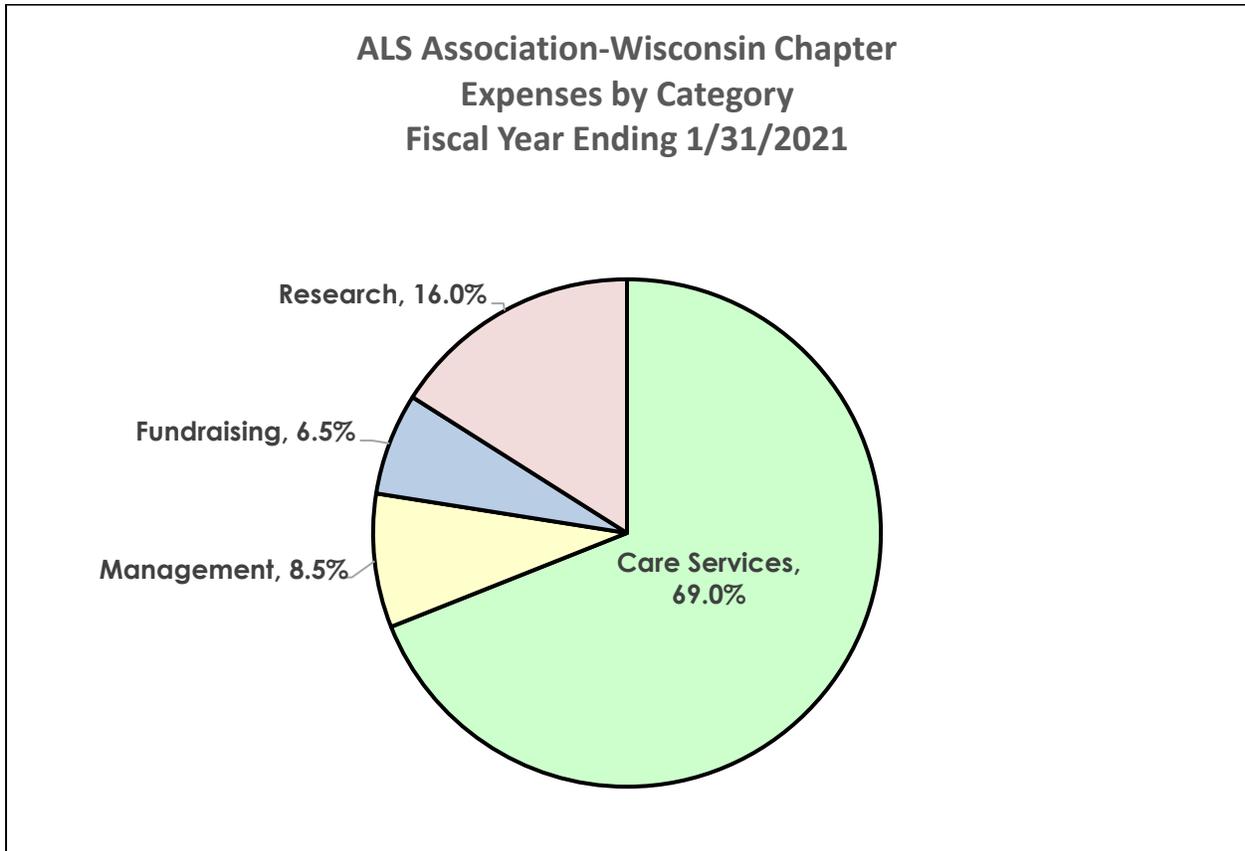
Year Ended January 31, 2021	Program Services					Management and General	Fundraising	Total
	Patient and Community Services	Advocacy/ Education and Awareness	Research					
Payroll and payroll taxes	\$ 310,907	\$ 194,829	\$ -	\$ 57,305	\$ 90,359	\$ 653,400		
Clinic	7,484	-	-	-	-	7,484		
Computer equipment and software	3,234	-	-	5,524	-	8,758		
Conferences and continuing education	1,479	1,398	-	-	-	2,877		
Depreciation	131,563	-	-	1,259	-	132,822		
Education and awareness	-	116,810	-	-	-	116,810		
Equipment - Patient	51,725	-	-	-	-	51,725		
Equipment maintenance	19,828	-	-	-	-	19,828		
Flex grant	36,013	-	-	-	-	36,013		
Insurance	16,188	7,973	-	6,884	4,369	35,414		
Leadership team	-	-	-	1,330	-	1,330		
Loss on disposal of equipment	90,077	-	-	-	-	90,077		
Miscellaneous	960	268	-	637	391	2,256		
Office rent	18,495	10,223	-	2,586	4,741	36,045		
Printing and postage	1,087	-	-	754	-	1,841		
Processing fees	6,135	-	-	-	-	6,135		
Professional fees	126	-	-	44,861	-	44,987		
Research - National ALS	-	-	249,836	-	-	249,836		
Reimbursements	1,156	-	-	923	-	2,079		
Social worker	29,172	-	-	-	-	29,172		
Supplies	2,151	-	-	2,697	-	4,848		
Support group	1,760	-	-	-	-	1,760		
Support group facilitator	375	-	-	-	-	375		
Telephone	8,223	-	-	6,710	-	14,933		
Transportation grant	8,388	-	-	-	-	8,388		
Youth program	45	-	-	-	-	45		
Cost of special events	6,135	-	94,271	-	220,212	320,618		
<b>Total expenses by function</b>	<b>752,706</b>	<b>331,501</b>	<b>344,107</b>	<b>131,470</b>	<b>320,072</b>	<b>1,871,098</b>		
Less - Cost of special events netted against support and revenue on the statement of activities:	(6,135)	-	(94,271)	-	(220,212)	(320,618)		
<b>Total expenses on the statement of activities</b>	<b>\$ 746,571</b>	<b>\$ 331,501</b>	<b>\$ 249,836</b>	<b>\$ 131,470</b>	<b>\$ 99,860</b>	<b>\$ 1,559,238</b>		

\*The organization benefited from in-kind contributions and contributed services totaling \$318,947, included in the schedule above as follows:

Patient and community services	\$15,868
Advocacy/education and awareness	88,641
Research	39,020
Management and general	25,550
Fundraising	<u>149,868</u>
Total	\$318,947

## HOW THE CHAPTER USES ITS FUNDS

The Chapter's primary revenue source is donations from individuals and entities. The Chapter Board of Directors is committed to utilizing all specifically designated funds in accord with the donors' wishes and utilizing all non-designated funds in the manner the Board believes best serves the people in Wisconsin living with ALS and their families.



## **BOARD OF DIRECTORS**

February 1, 2020 – January 31, 2021

Kathryn A. Keppel  
President  
Partner, Gimbel, Reilly, Guerin & Brown LLP  
*Resigned January 2021*

Mary Brennan Druml  
President Elect (former Vice President)  
Community Volunteer

Meg Posorske  
Vice President  
Organization Transformation Leader

Lauren Domnick  
Treasurer  
Senior Director, Northwestern Mutual

Matthew O'Neill  
Secretary  
Attorney, Fox O'Neill Shannon S.C.

Carl Bahneman  
Director, Product Line Manager, FIS

Holly Blake  
Community Volunteer  
*Resigned November 2020*

Joel Hess  
Principal, LeaseCrunch  
*Resigned September 2020*

Thomas D. Kettler  
Community Volunteer

Mary Beth Schlecht  
Community Volunteer

Manis Mullarkey  
Mutual Fund Trader, US Bank

Jessica Geres  
Security, US Bank

Christopher Simms  
Regional Vice President, Numotion

## CHAPTER STAFF

February 1, 2020 – January 31, 2021

Melanie Roach-Bekos  
Executive Director

Angie Pereira, BSN, RN  
Care Services Director

### Development/Public Awareness Team

Susie Reed  
Development Manager

Taylor Skorik  
Marketing/Fundraising Coordinator

Cheryl Brooks  
Outreach Community Coordinator

### Administration

Kathleen Huevler  
Finance Manager

### Care Services Team

Robyn Stanczyk, RN  
Care Services Coordinator

Mary DeFrain-Jones, CSW  
Care Services Coordinator

Diane Fergot, CSW  
Care Services Coordinator/

Carolynne Younk, MS  
Care Services Coordinator

Shannan Morgan  
Care Services Coordinator

Janet Gauger  
Care Services Assistant

David Ferrie  
Equipment Program Coordinator

Meg Posorske  
Support Group Facilitator (*volunteer*)

Connie Troyanek & Carolyn Herman  
Support Group Facilitator (*volunteers*)

**2021 MEETINGS OF THE BOARD OF DIRECTORS**

*Thursday, March 18, 2021*  
5:30-7:00 p.m.

*Thursday, May 27, 2021*  
5:30-7:00 p.m.

*Thursday, July 29, 2021*  
5:30-7:00 p.m.

*Thursday, September 30, 2021*  
5:30-7:00 p.m.

*Thursday, November 18, 2021*  
5:30-7:00 p.m.

*Thursday, January 27, 2022*  
5:30-7:00 p.m.